



Hello!

Being the Body of Christ:

How can we include people living with invisible illnesses and chronic conditions in our church communities?

Seminar for Harrogate School of Theology and Mission, based on a study led by Penny Pullan

Invisible Illnesses and Chronic Conditions?



ME/CFS is a complex and chronic medical condition that effects multiple body systems.

Symptoms include flu-like malaise, sleep difficulties, brain fog and a profound fatigue that is unlike normal tiredness. People may also experience chronic pain, headaches, nausea, digestive problems, and sensitivity to light, sound and other stimuli.

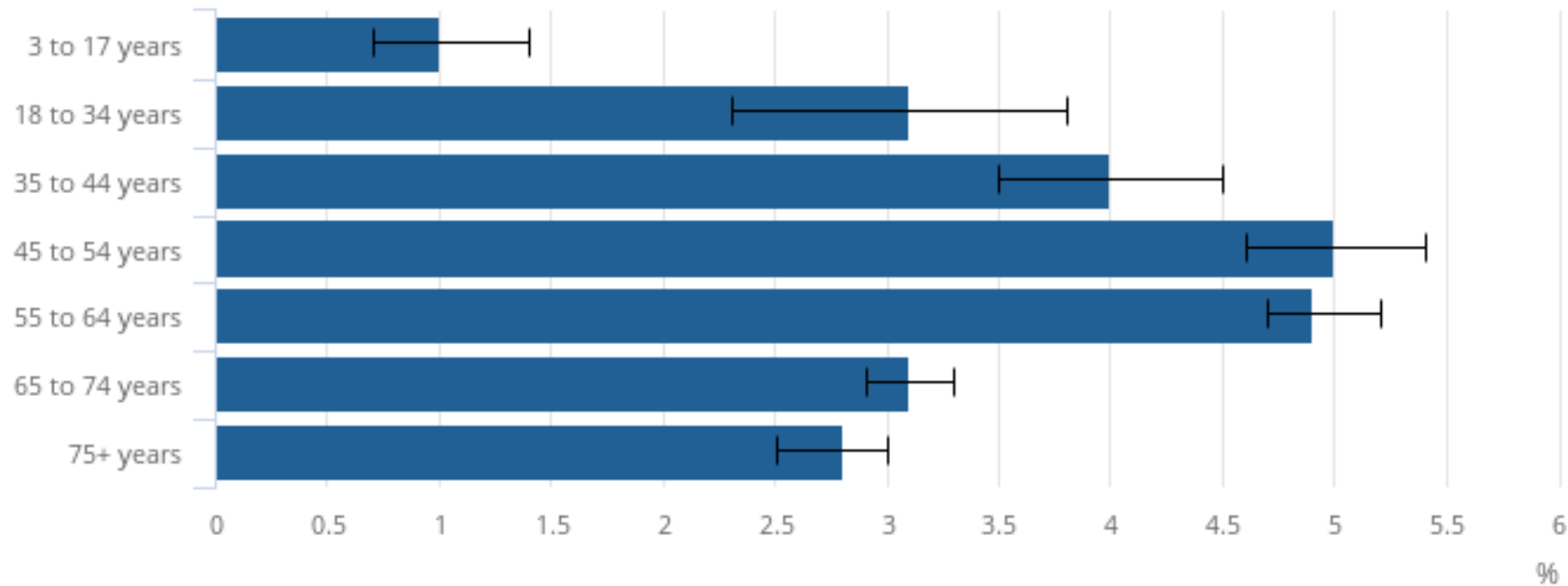
<https://meassociation.org.uk/me-cfs-long-covid-overview/>

Long COVID is defined as the continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation.

<https://www.who.int/europe/news-room/fact-sheets/item/post-covid-19-condition>

Figure 2: Those aged 45 to 54 years are most likely to report long COVID

Estimated percentage of people living in private households with self-reported long COVID of any duration by age, England and Scotland, four-week period ending 7 March 2024



Source: Winter Coronavirus (COVID-19) Infection Study (Winter CIS) from the Office for National Statistics



ST HILD

Why?

CHURCH TIMES

[Home](#) [UK](#) [World](#) [Comment](#) [Features](#) [Faith](#) [Books & Arts](#) [Regulars](#) [Audio](#)

Health: Surely, things will get better?

15 OCTOBER 2021

How does Christian faith sit alongside chronic illness? *Penny and Malcolm Pullan* recount their stories

Penny's story

I MET Malcolm when we were postgraduate students at Cambridge, in January 1990. I was studying for a Ph.D. in engineering (nanotechnology), and his doctorate was in mathematics (operations research). We met remotely on the Cambridge University mainframe computer, and discussed life, the universe, and everything, in between working on our Ph.D.s. Within six months, Malcolm had



Is Inclusion Enough?





**“To be included, you just need to be present.
To belong you need to be missed.”**

John Swinton

‘From Inclusion to Belonging: A Practical Theology of Community, Disability and Humanness’ in *Journal of Religion, Disability and Health*, 16(2) 2012, pp. 172-190 p. 177



The Research Question

How are people of working age
with invisible illnesses and chronic conditions
(particularly those with Myalgic Encephalomyelitis (ME)
and Long COVID)
included in their Church of England church communities,
whether in-person, hybrid and/or online,
and how much do they feel they really matter and belong?



The Study



January – June 2024

Could you help with this study?

Do you have an
invisible illness or
chronic condition?

Is your condition
ME, Long COVID or
similar,
or immune
compromised due
to chemo?

Are you a member of a
Church of England
community?

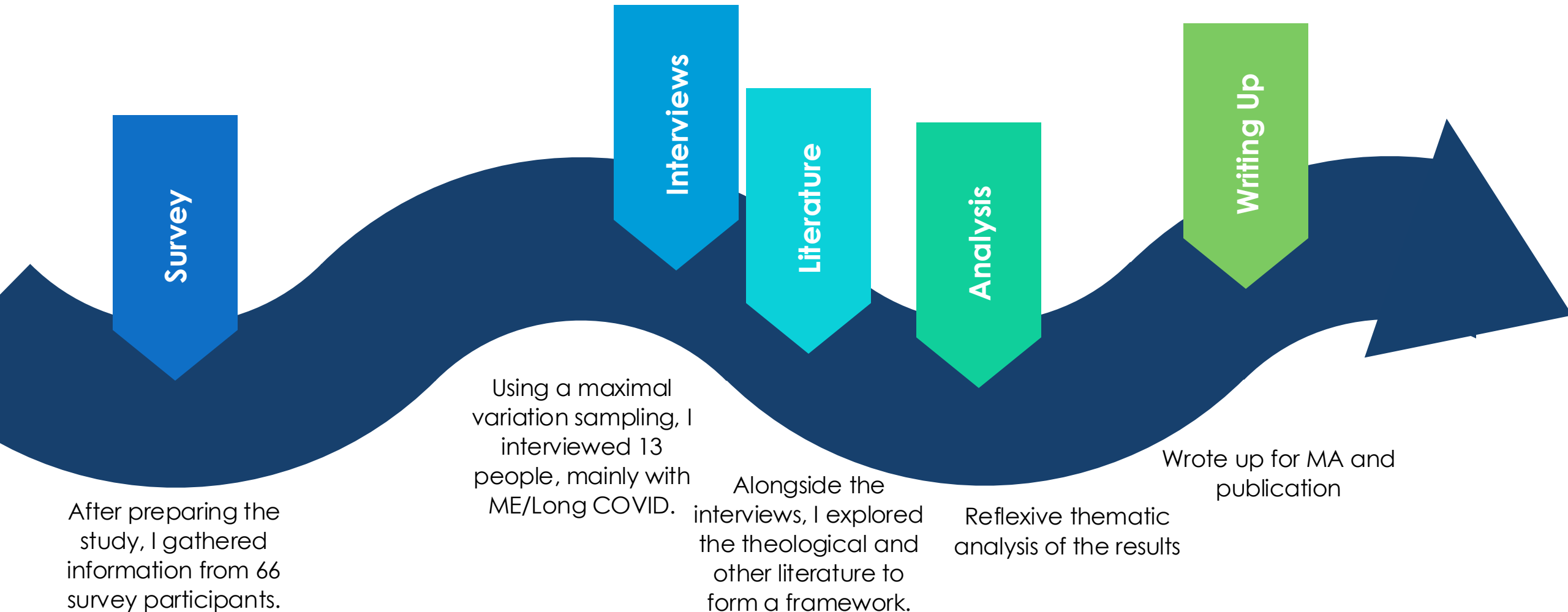
Are you of working
age, 18-65?

Are you able to
complete a survey
online?

If so, you are just who we are looking for!

ethicsofinclusion.study

Study Progress 2024



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Teaching needs to be accessible
 Lucky to be part of this church
 Over-estimating inclusion
 Change to supportive leader
 Hybrid for meetings
 Feeling grief and loss
 Inclusion means LGBTQI+++
 Gifts/ministry not used
 Non supportive church leader
 PCC member
 "I have disappeared/been forgotten"
 Church Worker
 Supportive church leader
 Mitigations lacking for COVID
 "You look well!"
 Costs of church involvement
 Healing (or not)
 Inclusion looks like...
 Disabled is not their idea of priest/minister
 I'm unreliable'
 how affected?
 COVID deterioration
 Reader/LLM
 How Valued
 Need more flexibility and understanding
 Seen
 Unseen
 What else?
 Can't attend in person church
 Pain
 Stigma
 Notes
 Church is tiring
 Next step
 Great Quotes
 Leading music
 Pacing
 Exclusion
 Lay Role
 Frustration
 How Included
 Lament/suffering - talking about it openly
 Isolated
 Online is valuable
 Valued for what I do/my role
 Ordained
 Rotas are bad
 "I have to say no"
 Gifts/ministry used
 Value other illnesses more
 Sit or stand, that's fine
 Disability Theology
 Stand - no allowances made
 Secular alternative better
 Belonged when well
 Church services that work for ill people
 Decisions made for me
 No or less online provision
 Leader - lived experience
 Teacher in church school
 Valued for who I am, rather than what I do

The Results: Themes



Themes

The Challenging Ones



I'm valued for what I do, not who I am

Rotas are a nightmare

Church harms...

I'm treated differently from others

'I have disappeared'

I'm valued for what I do, not who I am

“

“There's a lot of pressure. You only seem valued if you do stuff.”

– Participant P30

“[I'm] of no value to the church as I am not well enough to volunteer”

– Participant S14

”

Rotas are a nightmare

“

“I never know whether I'm going to feel ok or not so don't like commit to things. Hence, I don't get as involved as I might otherwise, and therefore feel less included.”

– Participant S07

People say: 'We won't bother because she's unreliable. She's a bit all over the place.'

– Participant P30

”

Church harms...

physically, mentally and spiritually

“

“All I want to do is cry all the way through the service because I'm in so much pain.”

– Participant P05

“There is no safe inclusion for people with chronic illnesses”
[speaking of COVID infections in church]

– Participant P35

“People disbelieving and continually praying for my healing and telling me to repent. It affected me so much emotionally... I really believed God hated me.”

– Participant S28

”

I'm treated differently from others

“

“People find it easier to cope with when they can see some outward sign or something.”

– Participant P30

“When they try to include me, I feel different as it's always a special effort that feels a trouble.”

– Participant S36

“They've been good with them, but terrible with me!”
[comparing her treatment to those with visible disabilities]

– Participant P20

”

‘I have disappeared’

“

“Out of sight and out of mind. I feel I've been abandoned.”

– Participant P35

“Live-streaming [was] taken away”

– Participant S33

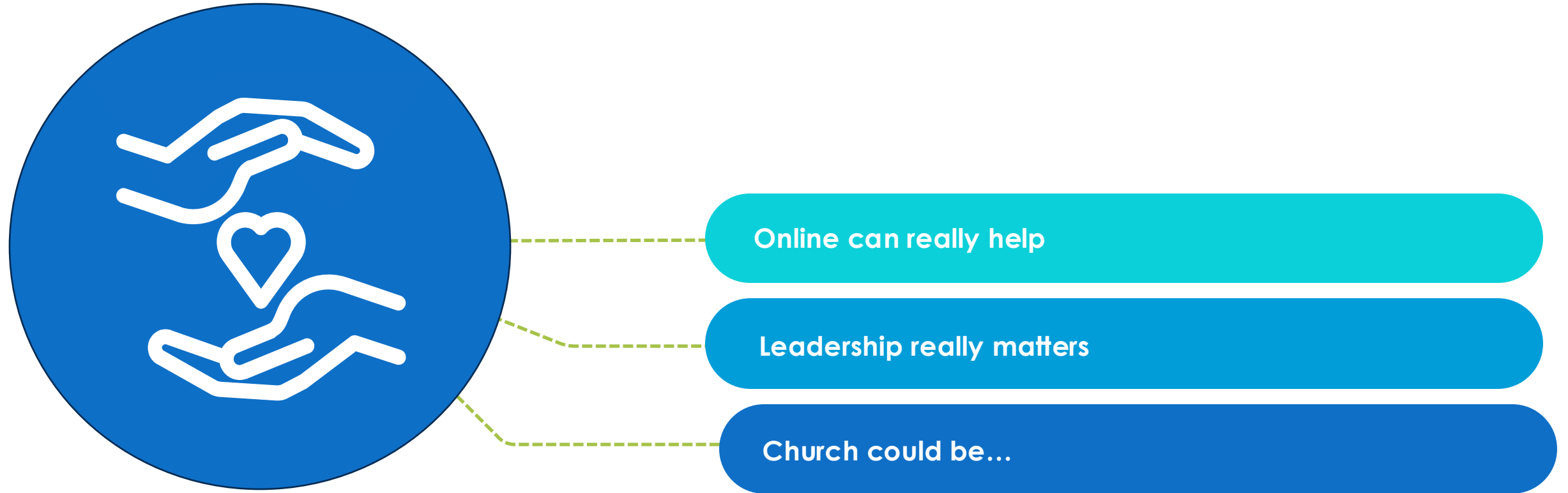
“I was told I can't go on the [home communion] list because they're too busy looking after all the older people who need it.”

– Participant P34

”

Themes

The Positive Ones



Online can really help

“

“Suddenly there was a level playing field. Everything was on Zoom and I could take part!” (March 2020)

– Participant P35

“We do art, we do Bible studies, we pray. It's just lovely. Lots of online chatting. It seems to really bless people.”

– Participant P34

”

Leadership really matters

“

“It makes such a difference! My vicar tells me: ‘If you want to sit down, just sit down.’”

– Participant P17

“Stand if you can - God doesn't mind if you don't.”

– Participant S46's vicar

”

Church could be...

“

“more welcoming, more joyful, more like Jesus”

– Participant P24

‘strength in weakness, beauty from brokenness, growth from suffering, great capacity from incapacity and so on. The upside-down kingdom’

– Participant S55

”

What can Churches do?

/ be



Some Ideas for Churches

Based on the themes...



Model

The Body of Christ
from 1 Corinthians 12



Stop the harm

Physical, mental,
spiritual and
emotional



Transform Culture

from
-individualistic
- doing over being



Rotas

Make rotas flexible
so more can serve.



The Same

Treat people well,
whether they have
cancer or ME.



Online

Use interactive
online sessions to
engage those
stuck at home.



Explore

What church
could be...



Listen

Listen to people
and their unique
set of needs.



Check

Who has
disappeared?
Did they want to
leave?

Analysis



Analysis Framework

Combining theology, social psychology, leadership and anthropology.

1. Culture

Typically individualistic, valuing doing over being.

3. Exclusion

Moving from exclusion to embrace, following Volf.

5. Inclusion/Belonging

True belonging as a disabled person, beyond inclusion

2. Social Identity Theory

Looking at in-groups and out-groups, stereotyping and stigma

4. Imago Dei

What does it mean to be a person made in the image of God?

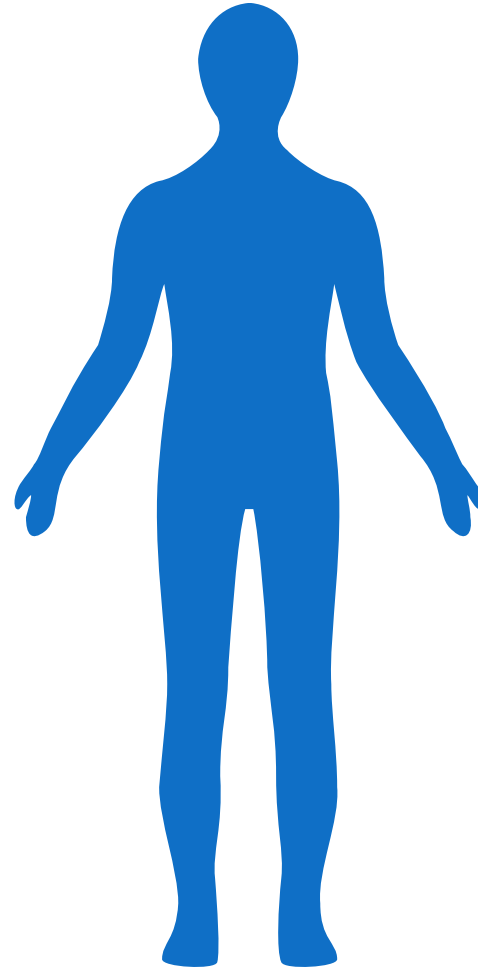
6. The Body of Christ

Equal across difference in Christ



Theology: The Body of Christ

Why everyone should belong



No hierarchy

All organs are just as important as all the others

Weaker

Are indispensable!
(but weaker doesn't necessarily mean disabled, which could be someone with less will power to resist temptation)

All are conduits

Of divine love. Disabled people need to play their full part in ministry.

One suffers...

All suffer, together. No concept of abandonment/surgical removal.



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p. 177





Made in the Image of God

Including those with invisible
illnesses and chronic conditions



Functional

Relational

Christological

Foretaste of
the Kingdom





Stop being indifferent!

**“The havoc wreaked by indifference
may be even “greater than that brought
by felt, lived, practiced hatred.””**

Miroslav Volf

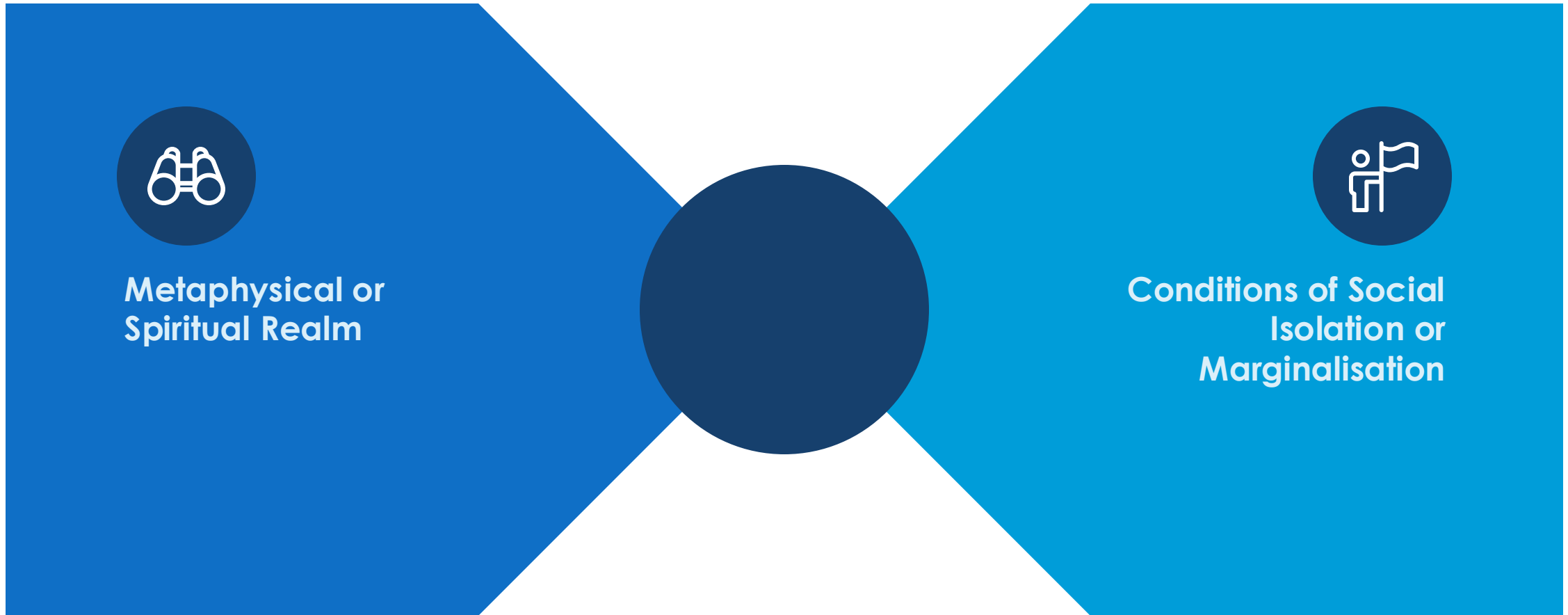
*Exclusion and Embrace: A Theological Exploration of Identity, Otherness and
Reconciliation* (Abingdon, 1996) p. 67





Invisibility



Invisible Theology



M. Cooper Harriss (2017). *Ralph Ellison's Invisible Theology*, NYU Press.



“The visible is a matter of what we see *in* what we see. If we would speak of the visible world, we need a notion of the invisible, but the invisible hides in the visible.”

Arne Grøn, ‘Phenomenology of In-visibility’ in eds.
Vind, A., Damgaard, I., Nielsen, K. B. and Havsteen, S.
R. *In-visibility* (Vandenhoeck & Ruprecht, 2020) p.20





“The invisible is not only that which hides in the visible, letting it appear. It is also what we make invisible.”

Arne Grøn, 'Phenomenology of In-visibility' in Vind, A., Damgaard, I., Nielsen, K. B. and Havsteen, S. R. (2020). *In-visibility* Vandenhoeck; Ruprecht p. 25





“making visible what has been hitherto invisible”

Kwok Pui-lan (Ed.) *Asian and Asian American Women
in Theology and Religion: Embodying knowledge*
(Palgrave Macmillan, 2020) Introduction



unseen

~~Invisible~~ Illnesses?



What can Churches do?



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Check

Who has
disappeared?
Did they want to
leave?

EthicsofInclusion.study



Email
penny@makingprojectswork.co.uk

Thank You!



To be published in P. Pullan, 'I Have Disappeared': Long COVID, ME and Inclusion in Church Communities' *Long Covid and Society: International Perspectives*, ed. D. Lupton (Palgrave Macmillan, 2025) and, potentially, a SCM book in 2026/7



Extras

Some Demographic and Ratings Results



Project: MA Study

Users: 1
Media: 62
Descriptors: 61
Excerpts: 329
Codes: 35
Code Application: 329

Import Data Spreadsheets, Documents, Audio, Video, Projects, etc.

Export Data Excerpts, Media, Codes, Descriptors, Project, etc.

Codes

- Belonged when well
- Can't attend in person church
- Great Quotes
- How do others see me?
- Valued for what I did for others/role
- Leader impact
- Leader not supportive now
- Non supportive church leader
- Supportive Church Leader
- Negative Experience of Church In-Person
- Can't take part
- Distant from God
- Giving too much
- Lonely

Media

Type	Title	Added	User	# Ex
Participant: 10		02/17/202	pennypullan	6
Participant: 11		02/17/202	pennypullan	4
Participant: 12		02/17/202	pennypullan	8
Participant: 13		02/17/202	pennypullan	4
Participant: 14		02/17/202	pennypullan	5
Participant: 15		02/17/202	pennypullan	6
Participant: 16		02/17/202	pennypullan	5
Participant: 17		02/17/202	pennypullan	6
Participant: 18		02/17/202	pennypullan	6
Participant: 19		02/17/202	pennypullan	7
Participant: 20		02/17/202	pennypullan	6

Excerpts: 329

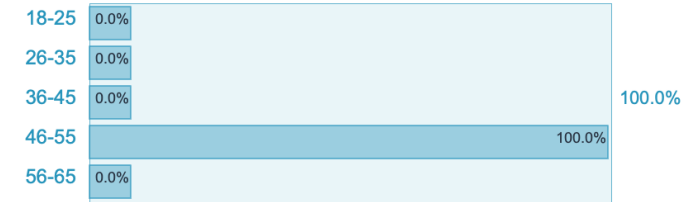
Resource	Participant: 61	Added	04/09/2024	Username	pennypullan	# Codes	1
	I am unable to physically attend church. I have not been able to attend for 22 years.						
Resource	Participant: 60	Added	04/09/2024	Username	pennypullan	# Codes	1
	because I've been ill for so long, no one ever visits me, and never has done. Even our vicar who has since left never came to see me.						
Resource	Participant: 60	Added	04/09/2024	Username	pennypullan	# Codes	1
	I rarely attend services, as most are in the morning and therefore I am unable to wake in time to go.						
Resource	Participant: 58	Added	04/09/2024	Username	pennypullan	# Codes	1

Codes x Descriptor

Hit/Miss ☐ Sub-code Count ☐ Normalize ☐ % ☐

Set: Default
Field: Age

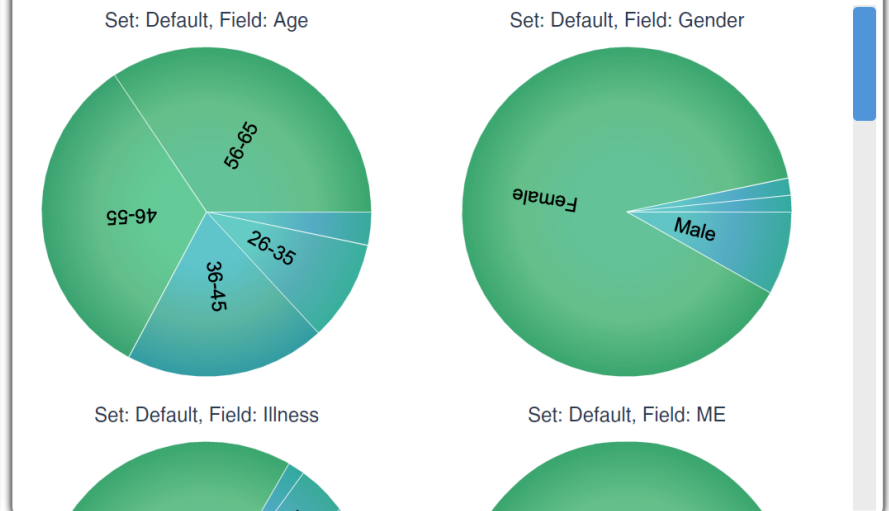
Belonged when well



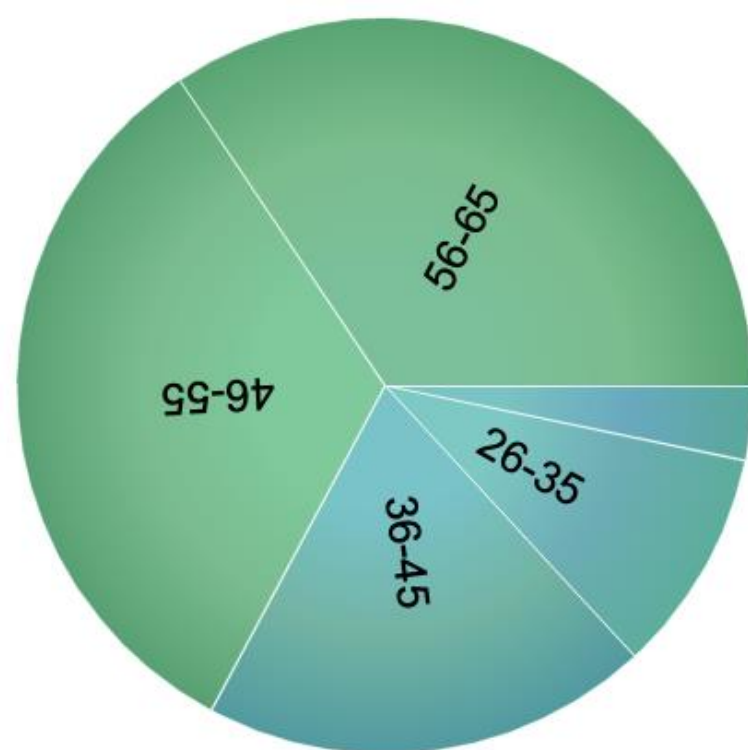
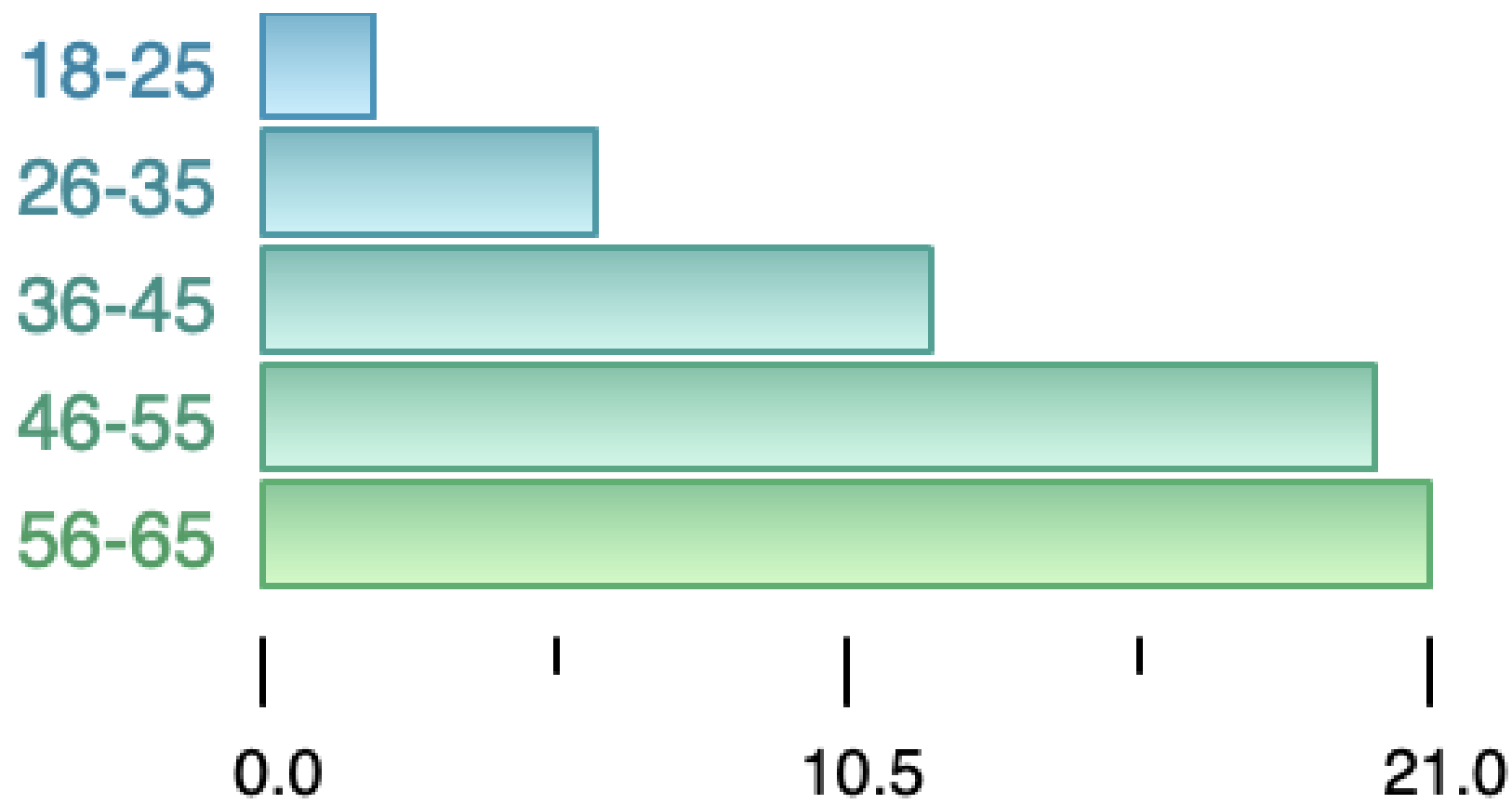
Can't attend in person church



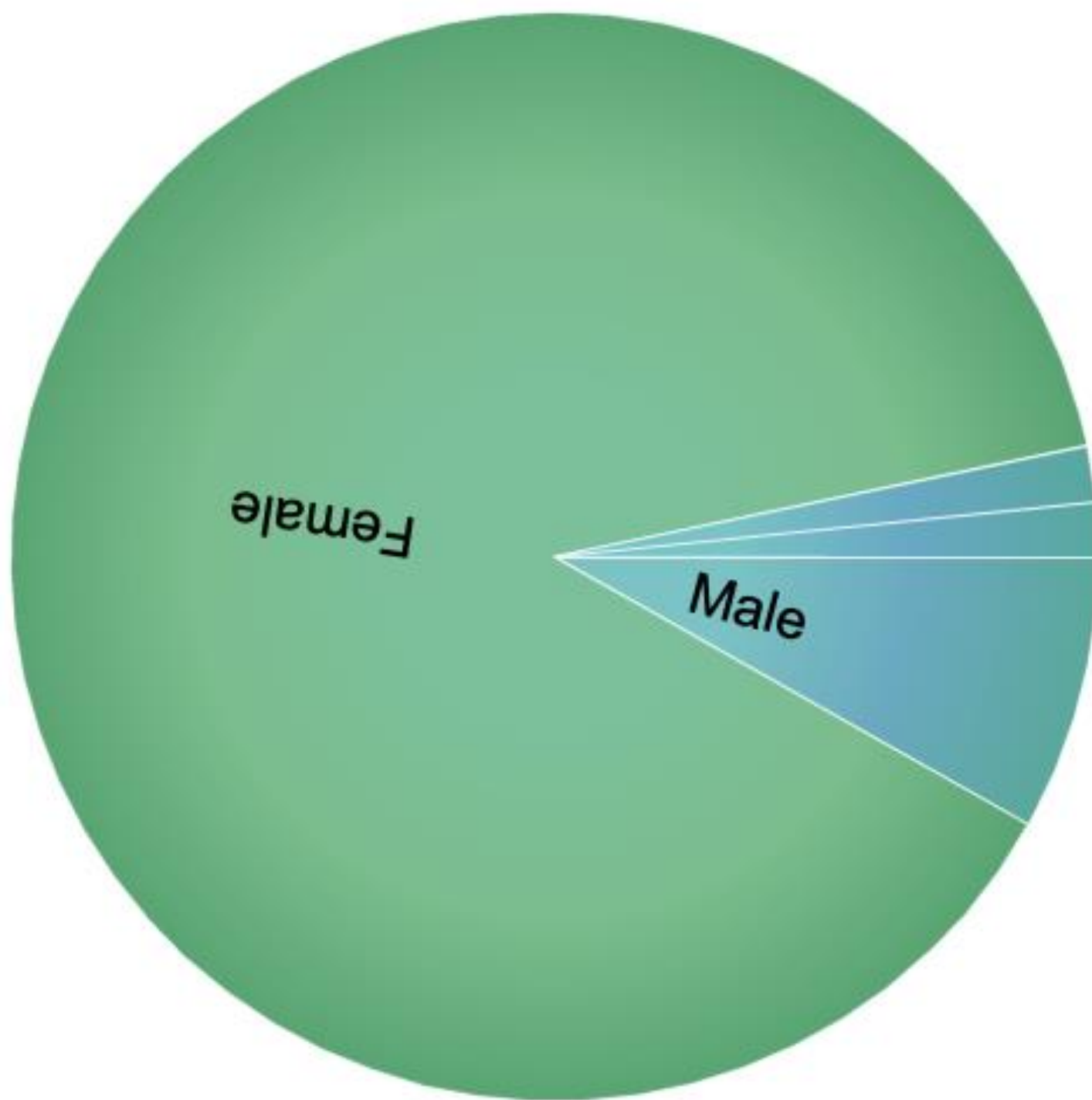
Descriptor Ratios Multi Chart



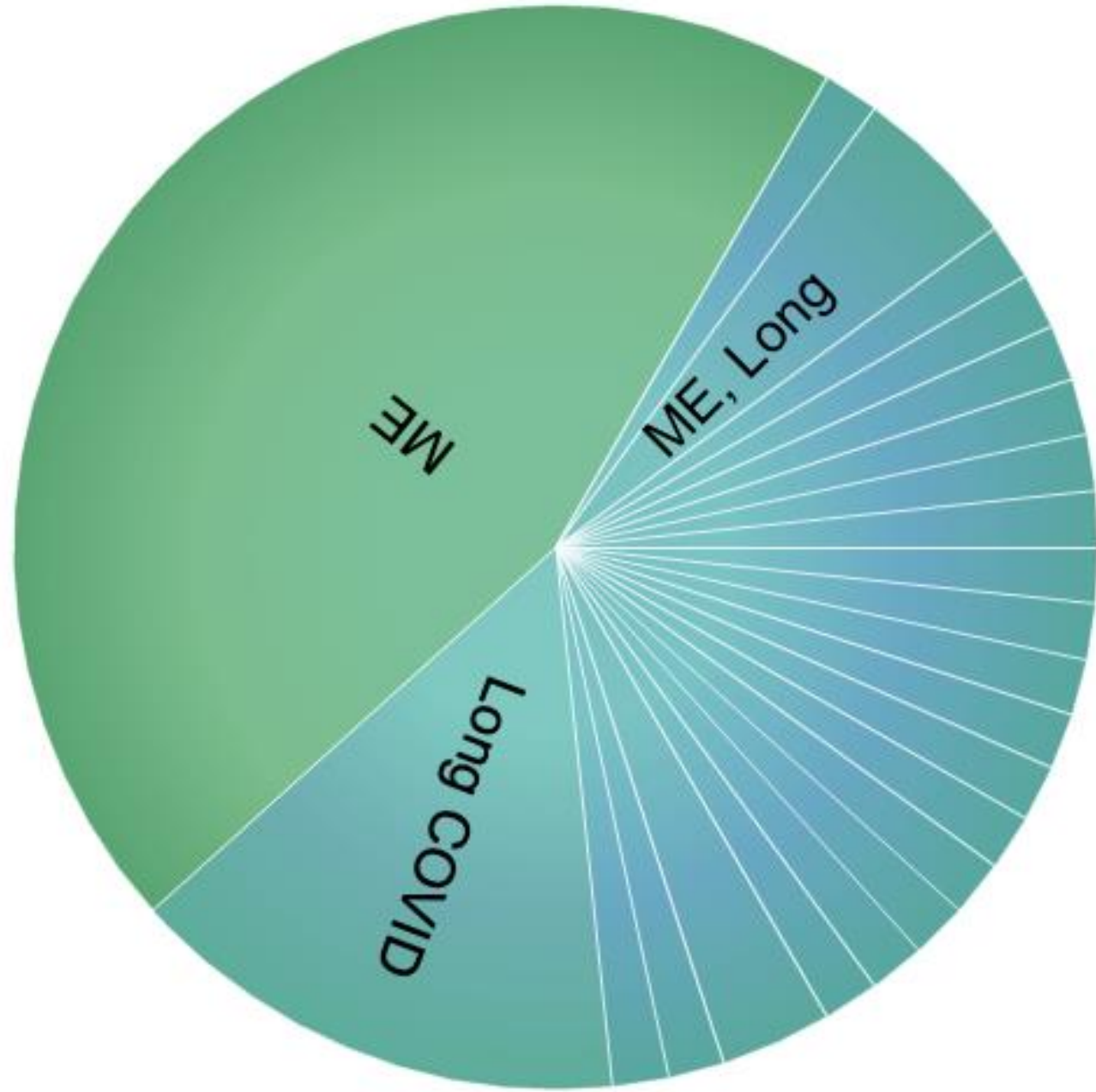
Age



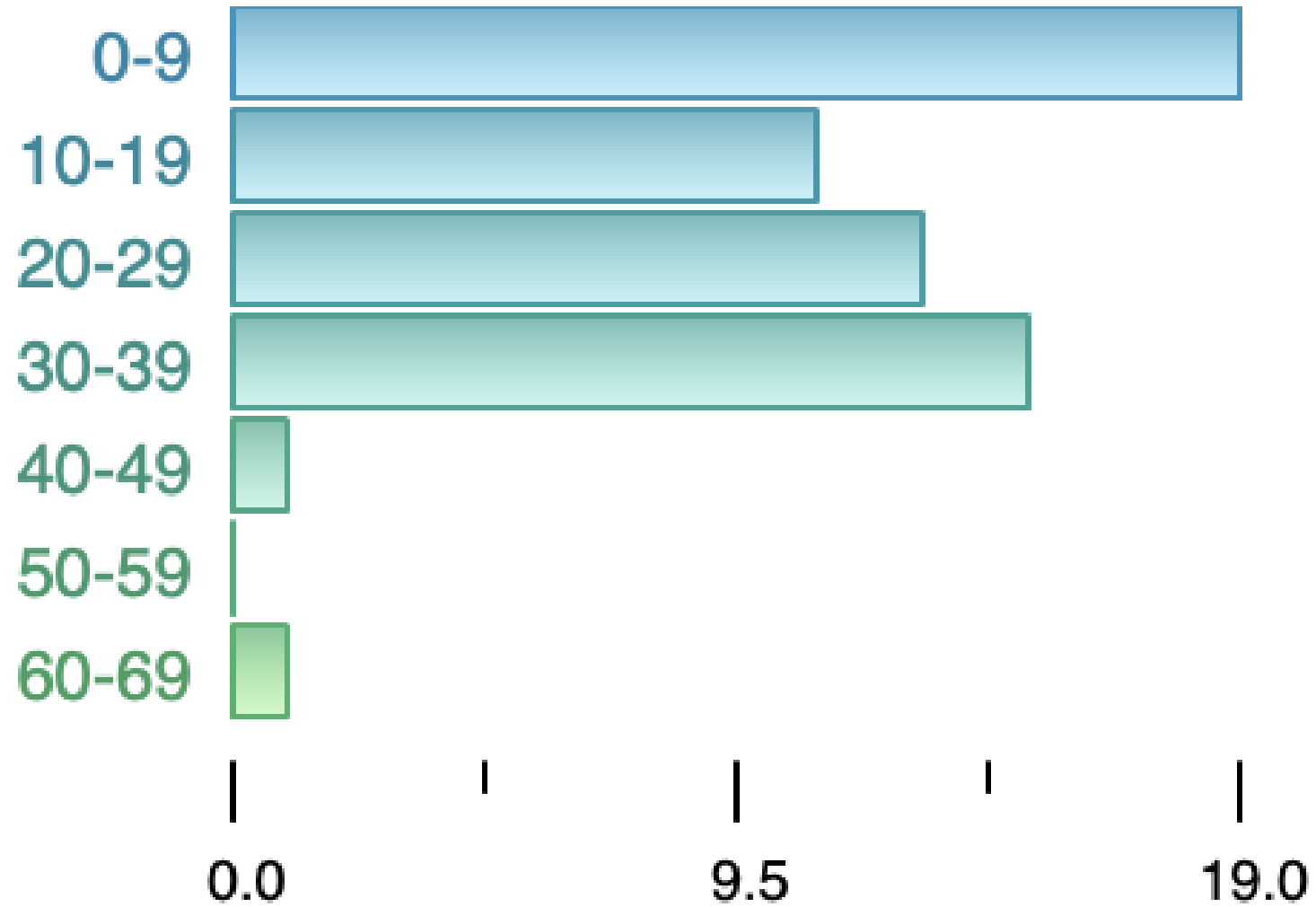
Gender



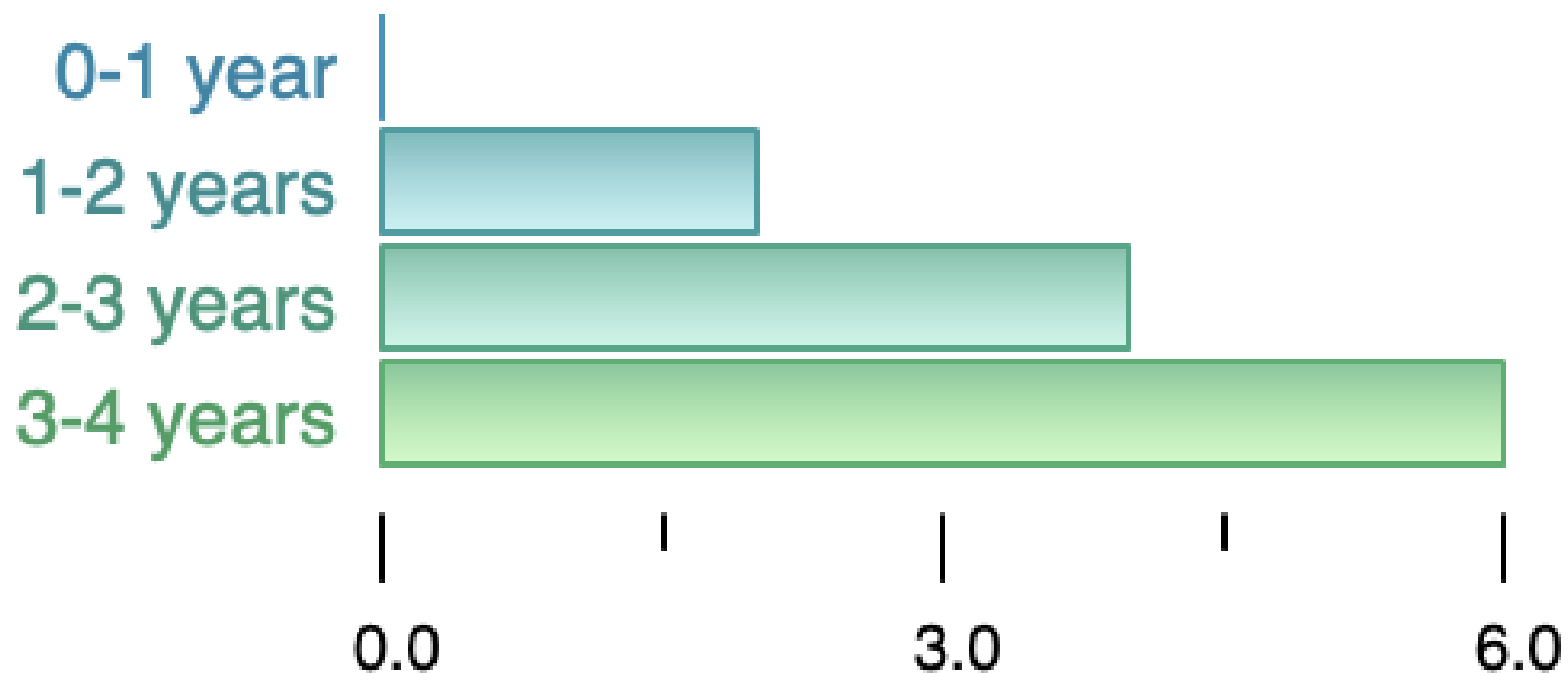
Invisible Illness or Unseen Condition



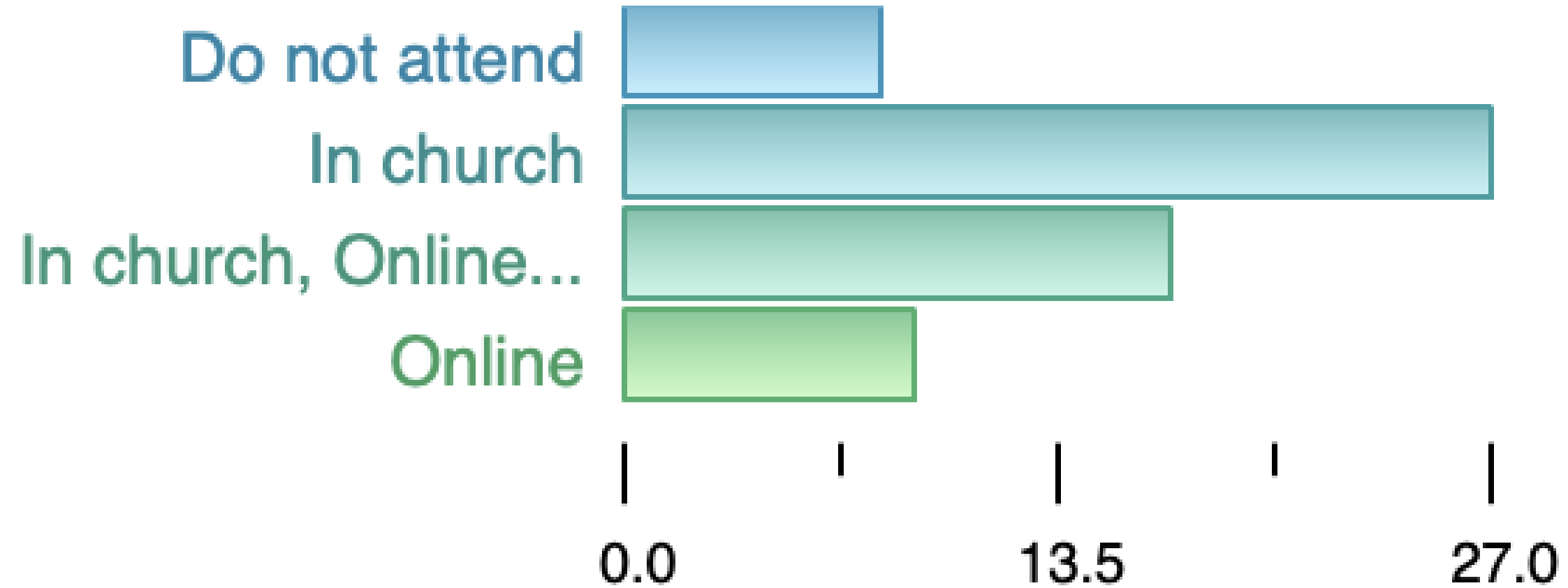
Length of Illness



Length of illness for those with Long COVID



How did they attend church?



On a scale of 1-5, how included do you feel in your church community, where 1 is 'not at all' and 5 is 'I am included wholeheartedly by everyone in my church community, despite my invisible illness'

1

2

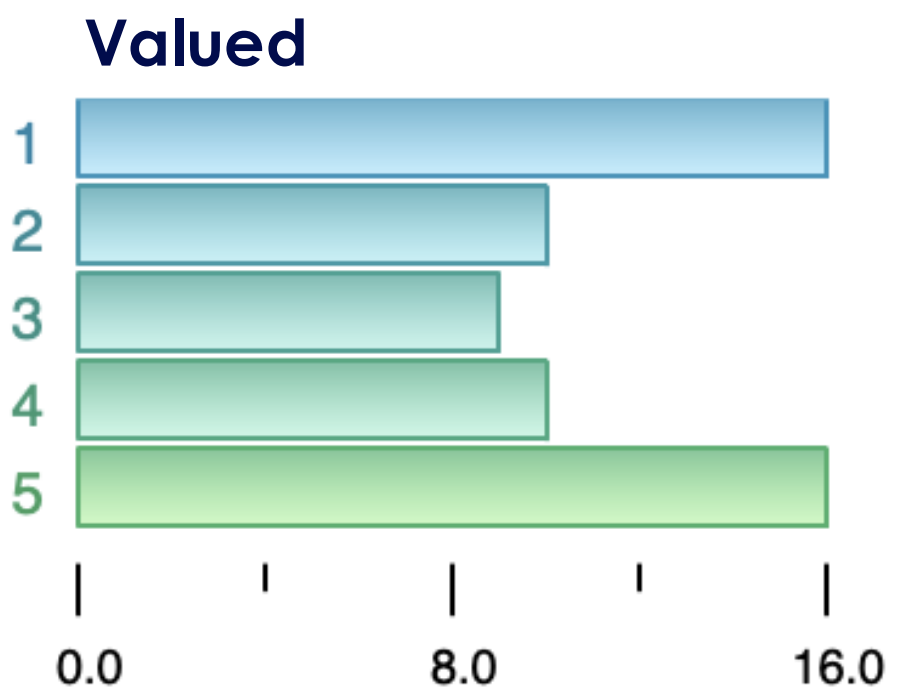
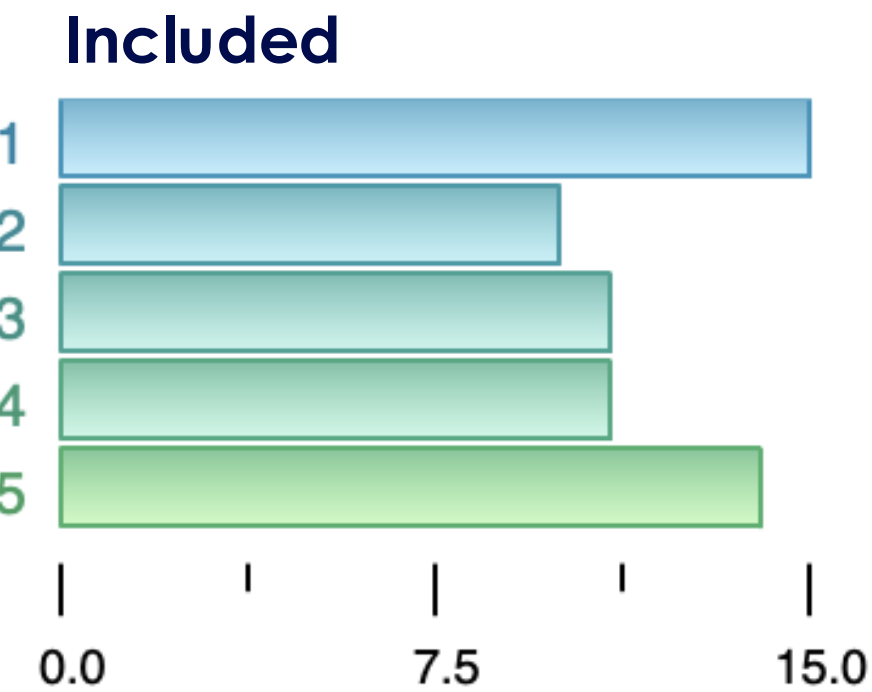
3

4

5

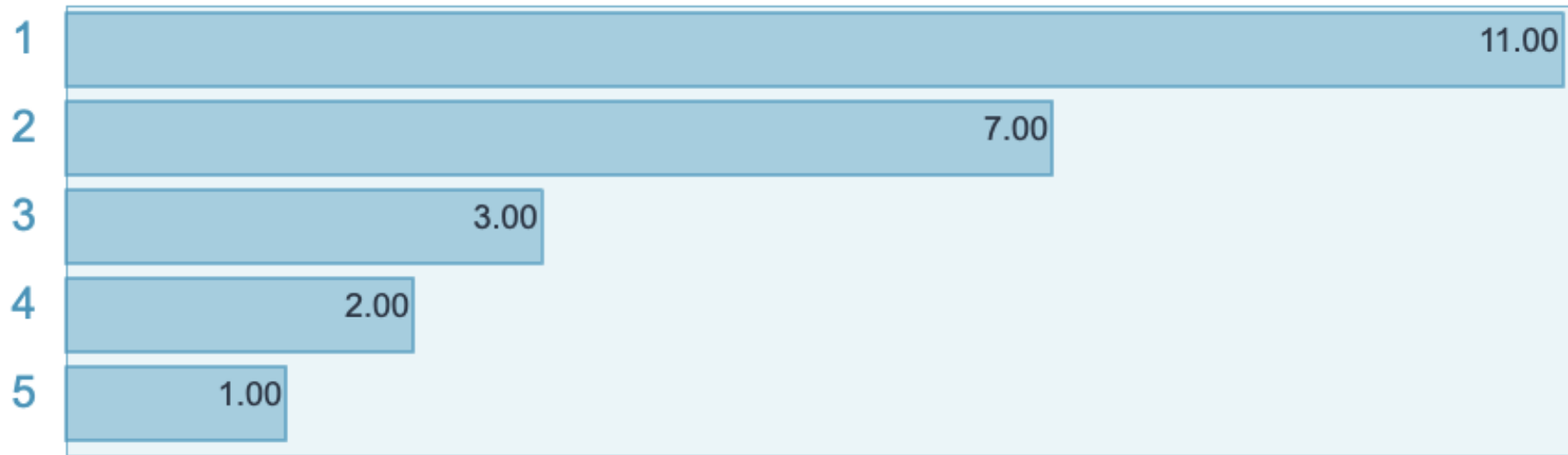
Not at all

I am included wholeheartedly

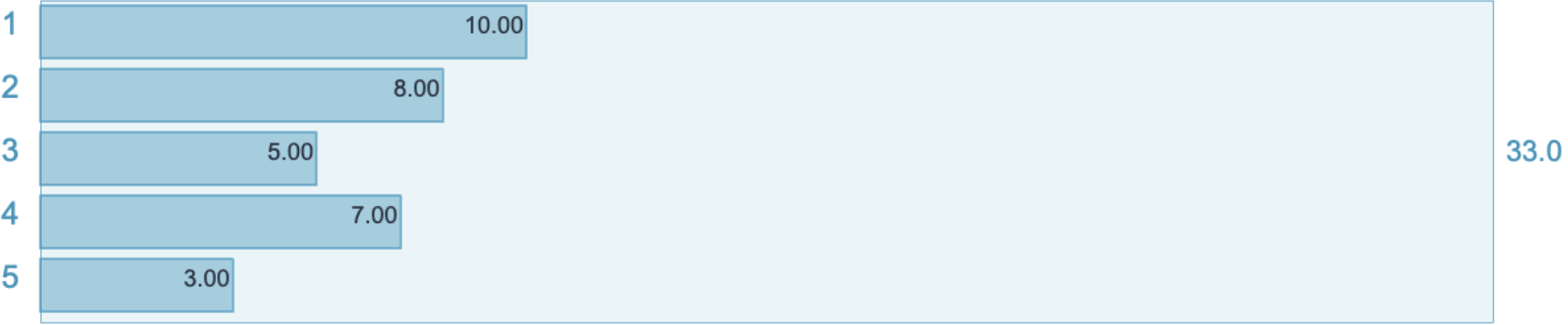


Included?

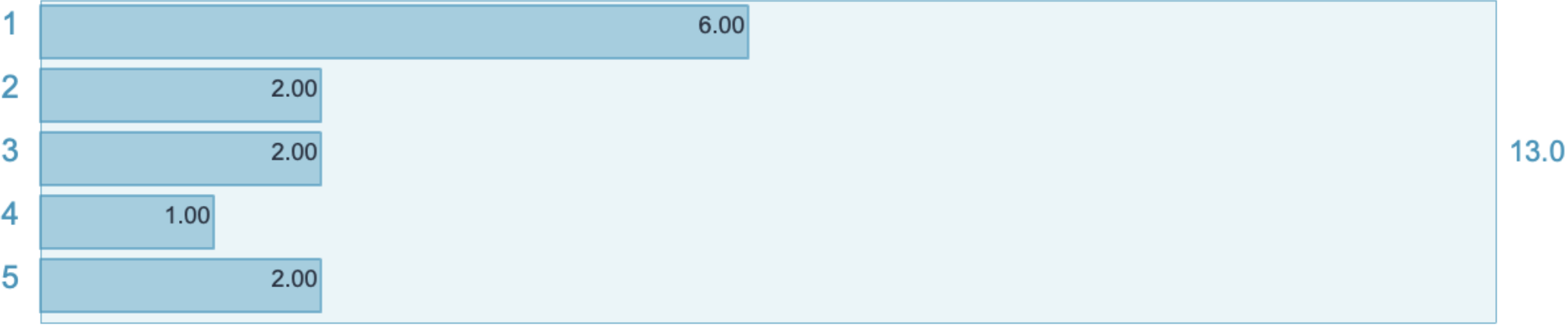
Can't attend in person church



ME



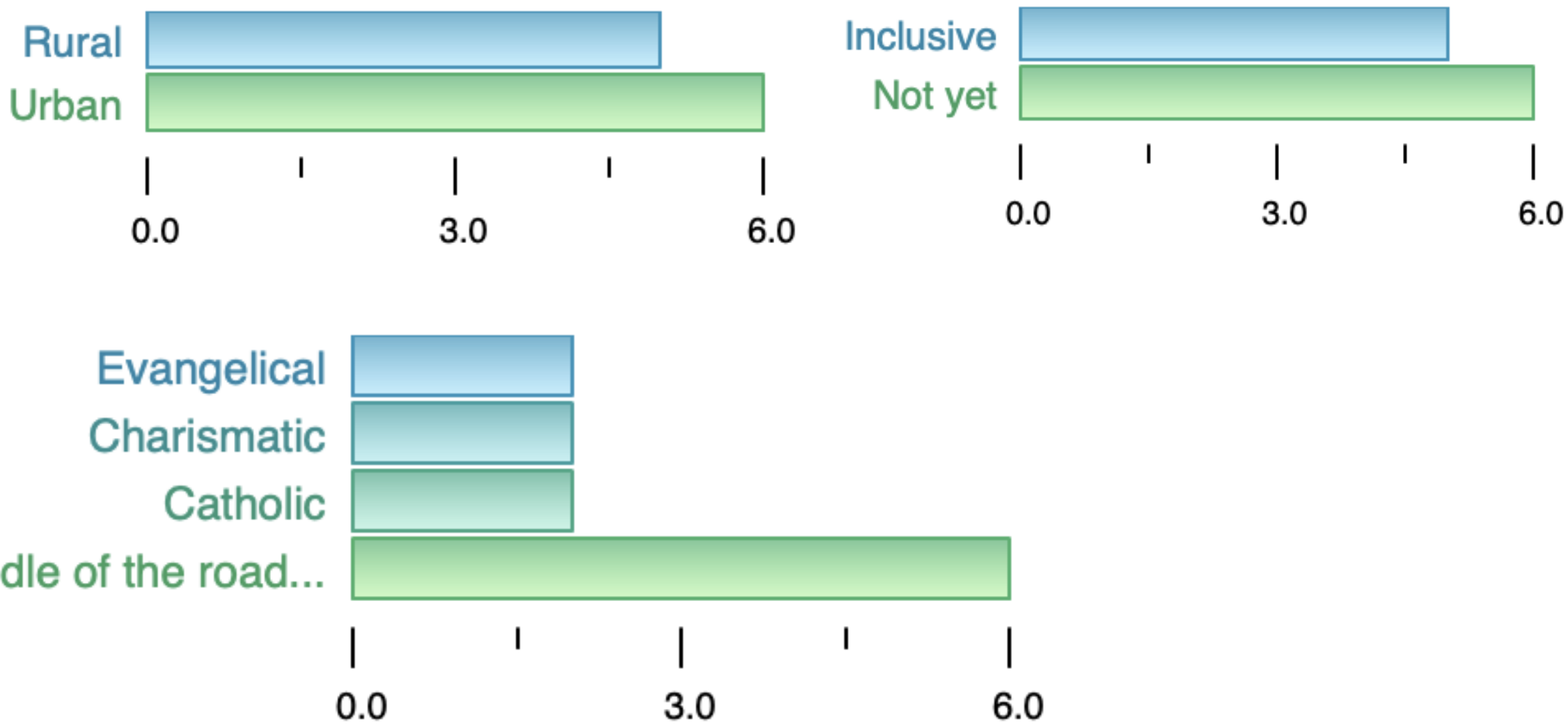
Long COVID



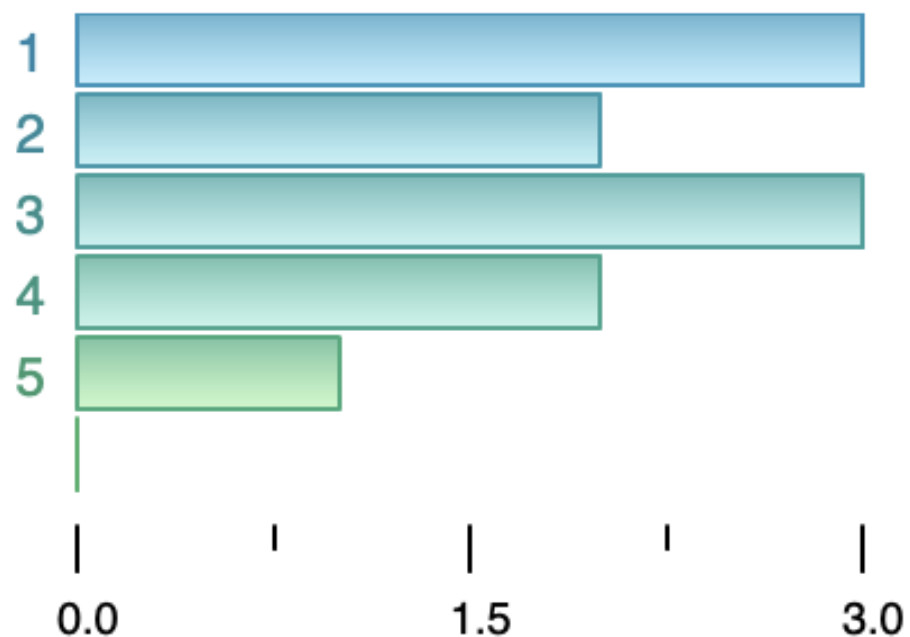
Chemo



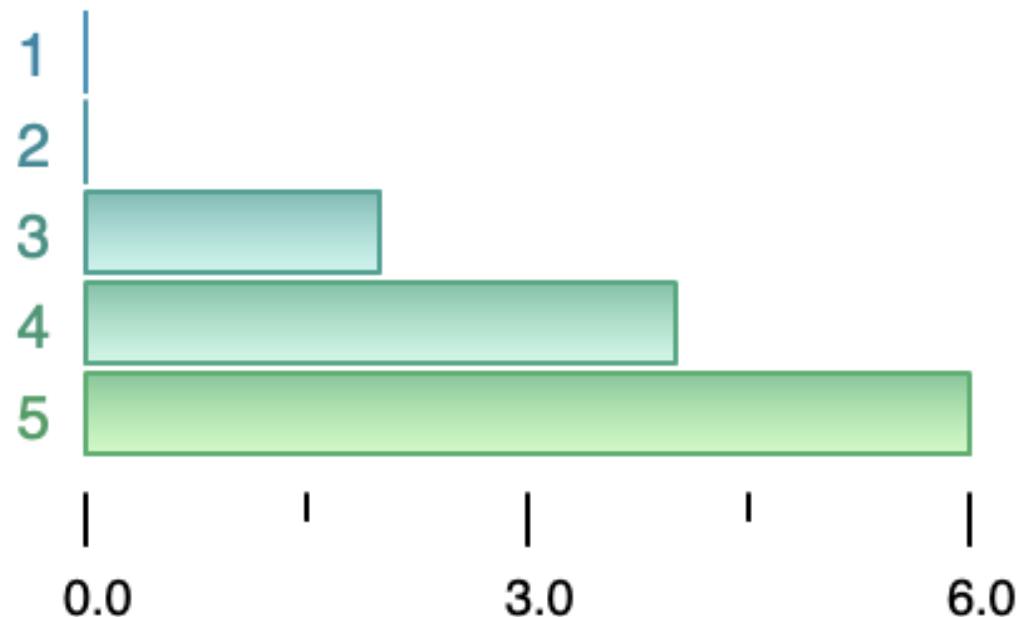
How did interviewees describe their church?



How welcoming is your church?



My experience of welcome as someone with an invisible illness



How my church would rate themselves on their welcome of disabled people

Gathering Participants





John Beauchamp

Diocesan Disability Ministry Enabler





ME Association

9 January ·



Ethics of Inclusion Study - We have been asked to share this link with our followers and we would be very happy to help any religious group with a similar type of survey.

"The study seeks to explore whether people of working age with invisible illnesses are included in their church communities in the Church of England.

"I'm focusing on people with chronic conditions that are not immediately obvious, including ME, Long Covid or people immunocompromised due to chemotherapy. Their church communities might include in-person, hybrid and/or online churches.

"I wonder how much do these people feel they really matter and belong?"

<https://www.ethicsofinclusion.study/>

#pwME #MECFs #MyalgicE #MyalgicEncephalomyelitis #LongCovid #PostCovid #CofE #ChurchofEngland



ETHICSOFINCLUSION.STUDY

Ethics of Inclusion

The study seeks to explore whether people of working age with invisible disabilities are included in their church communities in the Church of England.

[REDACTED]

Penny A Pullan Yes thanks it was very ME friendly and I've completed it. I have also put myself down for a video interview if required. Coming from a non-inclusive to an inclusive church has been a very interesting journey, the change is remarkable, from individual attitudes to systemic ones.



Our research work

[Text size](#)[Our projects and PhDs](#)[DecodeME](#)[Priority Setting Partnership](#)[UK ME Research Collaborative](#)[Advice for M.E. Researchers](#)[Get involved in research](#)

The Ethics of Inclusion: exploring whether people of working age with invisible illnesses and chronic conditions feel they belong in their church communities

Research question and details: How are people of working age with invisible illnesses and chronic conditions (particularly those with ME, Long COVID or the immunocompromised (due to chemotherapy treatment) included in their C of E church communities, whether in-person, hybrid and/or online, and how much do they feel they really matter and belong?

What's involved: To take part, people need to answer a questionnaire online, which has been described by participants as "short" and "very ME friendly". Please visit: www.ethicsofinclusion.study

If participants wish to take part further, they can put themselves forward to be one of the ten people interviewed over Zoom to gather deeper insights. This second step is purely voluntary.

Participant eligibility criteria: Participants must be of working age (defined as 18 - 65 inclusive for this study), members of a Church of England church (to some extent) and living with an invisible illness or chronic condition, such as ME or Long COVID.

Ethical approval: This project has received ethics approval from Yorkshire Theological Education Partnership (YTEP) and St Hild College, as part of my Durham University MA research.

Contact details: To take part in the survey, please visit: www.ethicsofinclusion.study

The researcher's email is penny@pennypullan.com

Deadline for taking part: The survey will close in March 2024.